Broadening the Medical Ethics Perspective Through Dance

W e d n e s

Broadening the Medical Ethics Perspective Through Dance

By Shawn Harmon

Answers Too Easily Attained?

One of the fundamental questions that is asked through the field of ethics is: 'How should we live?' This question must also be central to medical ethics, or 'bioethics'. However, we seem to believe that we have answered this question, and we have settled into a comfortable application of that answer across a range of clinical circumstances and technological deployments:

We should live independently and autonomously, without coercion or interference, with few imposed duties and little sense of obligation, free to avoid risk and to vigorously protect our physical and emotional integrity against state organs, private entities, and individuals.

While this is an oversimplification, the majority of substantive assessments will either explicitly or implicitly begin from a foundational proposition not far removed. The premise is not generally objectionable, but the lack of depth in our ethical reflexivity is disheartening. How have we embedded this premise so deeply that we proceed from it in most every medical and research encounter?

Is Law to Blame?

Bioethics has evolved into an interdisciplinary field that is increasingly distant from moral philosophy and broader questions of being, and increasingly entangled with legal principles and rules, specifically those emergent from human rights law. Legal instruments that view ethics within the human rights paradigm have become key shapers of ethical thought and practices (e.g., the Convention on Human Rights and Biomedicine 1997, and the UNESCO Universal Declaration on Bioethics and Human Rights 2005). Consequences of this legalistic turn include:

- A narrowing of the bioethics view; certain possibilities and deliberations are off the table because the *law* will not contemplate them. And because the law is informed by a particular moral foundation, other moral positions that *might* lead to alternative answers (e.g., communitarianism or solidarity) are not considered.
- A focus on instrumental issues relating to treatment, focusing on individual capacity, modes of consent, and techno-grounded questions around the allocation of responsibilities with respect to medical resources (i.e., cadavers, organs, tissue), all matters coloured by legal reasoning, principles, and structures.

Ultimately, bioethical issues are too often reduced to questions of moral agency and the propriety of action in a world of limited resources, and they are too often culturally decontextualized (divorced from the lived experience of patients as intentional, value-holding, moral agents).

Disability, Dance and a Wider View

This narrowing and relative invisibility of the person can have particularly profound impacts on disabled people because it permits them to be viewed as 'others' based on the form and functionality of their physiology. This 'othering' has led to the construction of a normative body that is very narrowly defined. The bioethics undertaking would benefit from a wider view permitting deeper deliberations about health and illness in their broader and experiential contexts. This wider view can be encouraged by the injection of more empirical evidence from interested communities; experience is a useful source of moral wisdom, and the embodied experiences of stakeholders can aid reflection, analysis, and the development and implementation of normative guidelines applicable to practice.

The InVisible Difference project seeks to extend thinking and alter practice around the making, status, ownership, and value of work by disabled dancers.

The evidence derived from InVisible Difference confirms the assertion of invisibility. Respondents reported that they learned how to speak to doctors using the "medical language", reported that they were "put on display" (with doctors and interns parading through their treatment space, the latter quizzed on what they observed), and reported that medical agents never truly engaged with their lived experience. InVisible Difference also offers lessons about the disabled body itself, the most important of which is that it can be remarkably robust, and not as 'other' as typically constructed, both medically and socially. By exposing themselves through dance, respondents affirm themselves as subjects entitled to respect and the full enjoyment of rights and opportunities, and as uniquely abled individuals with particular and valuable talents. Dance is "safe" for them because they can present themselves in ways that the medical gaze has been incapable of capturing and the bioethics gaze has been unwilling to contemplate. It is also "safe" for us because we have been invited to share a space; we are not interlopers sneaking glances at strange bodies, but rather viewers welcomed to look and to form a communion with them. Dance can introduce us to the idea that disabled bodies are not inevitably 'broken bodies' as commonly constructed, but rather richly diverse embodiments of humanity that offer a voice through which individuals speak.

Query

We need to more often engage with the question: 'How should we live?' Bioethics should serve as a site of social collaboration on both broad and narrow questions, and more systematised connections with stakeholders like the disabled will facilitate this. How do you suppose we should achieve this, and what communities of practice do you think are important to better engage with?

We welcome your views and input. Please contact me, Shawn Harmon, as Co-Investigator at shawn.harmon@ed.ac.uk.

Posted by Mason Institute at 04:09

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